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Positive Healthcare Encounters for Children With Autism Spectrum Disorder: Accommodations During Surgical Procedures

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A B S T R A C T

Children with autism spectrum disorder have unique needs during medical procedures involving anesthesia. However, with early patient identification, provider champions can adapt their practice to better serve this population, thereby improving patient satisfaction and outcomes. This article describes a novel protocol developed by an anesthesia resource center to modify care for children with autism spectrum disorder and their families. This information serves as a template for perianesthesia nurses and advanced care providers to implement practice accommodations. Two case examples, based on parent interviews and chart review, are presented to exemplify this protocol.

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by differences in sensory and social processing.[1] The prevalence of ASD in the United States is approximately 18.5 per 1,000, one in 54 children, but extends to 31.4 per 1,000 in states like New Jersey.[2] Boys are 4.3 times more likely to be diagnosed with ASD by age eight and prevalence has steadily increased over the last three decades.[2] While the etiology is not completely understood, this increase has translated to greater consumption of healthcare for children with ASD compared to typically developing peers. Specifically, children with this condition are more likely to use emergency and routine healthcare overall and are seen for more frequent visits.[3] Hospitalizations are uncomfortable for all children but are uniquely difficult for those with ASD. Children with this condition are, compared to their neurotypical peers, more sensitive to tactile experiences, auditory and olfactory stimulation, and visual components of their environment.[4] Needle-sticks for lab work, alarms from equipment, hospital smells, and florescent lights are only a few examples of challenges the hospital environment poses for children with sensory differences. Additionally, children with ASD benefit from routines, where they can expect daily consistency in activities and environment.[5] Continuity of care with the same providers throughout the hospital experience is helpful, as children with ASD may not as readily adapt to interactions with new people. Moreover, children with ASD are more likely to be under-responsive to pain medication and are often unable to communicate about their pain.[6] For these reasons, pre- and postoperative assessment may be challenging in this population, requiring providers to spend more time with each child. However, health care providers often report low levels of comfort adapting their practice for children with ASD, specifically in sensory components of care.[7]

Modifications of clinical environments and practice are critical to ensuring equitable access to healthcare for children with neurodevelopmental differences. Each health care center requires champions to create and lead accommodations to meet individual needs of children with ASD and their families. Among the clinical specialties that have been most effective at accommodating children with ASD is pediatric dentistry. In addition to having an independent risk for poor oral hygiene, children with ASD frequently avoid dental care due to its high sensory profile.[8] Dentists acknowledge that managing behavior is imperative to ensuring patients can tolerate procedures.[9] Among the most important interventions this discipline has implemented is early coordination with the family to develop a plan of care.[10] Likewise, in a survey of parents of children with ASD, diminishing environmental triggers and clear communication were identified as important parts of patient-centered practice.[11] The solutions developed in dentistry can be readily translated to other disciplines.[12] This is especially true during hospitalizations for procedures, where

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children with ASD experience heightened rate of anxiety compared to neurotypical peers.[13] In a systematic review of practices to help children with ASD through general surgery, techniques like increased attention to individual needs and distraction were effective.[14] In addition to these strategies, premedication may be administered to facilitate the transition into anesthesia if it is used.[15] With the identification of children with ASD, staff members can anticipate the potential and emerging challenges for children before surgery, improving staff competency and patient outcomes.[16] Increases in procedures for children with ASD and the sensory challenges that hospital settings present necessitates accommodations to care for this population. Receiving anesthesia has a high sensory profile that children with ASD find particularly challenging.[17] Therefore, it is reasonable to develop and implement a program of adaptations to care in this clinical area. The aim of this review is to describe patient-centered accommodations developed by an anesthesia resource center for children with ASD in a large urban pediatric hospital and to highlight two clinical cases.

Methods

To understand modifications to anesthesia practice, we conducted semi-structured interviews with members of an interdisciplinary medical team at the Anesthesia Resource Center (ARC). This team developed a set of modifications that have been implemented into their clinical practice over the last 2 years. Interview questions were designed to (1) describe standard practice for pediatric procedures and (2) understand changes to these procedures for children with ASD. These interviews included a nurse, advanced practice provider, and anesthesiologist. Interview themes were synthesized according to area and type of modification. Adopting methodologies from quality improvement, a process map was developed and overlaid with modifications for standard procedures.[18] Secondly, a series of interviews was conducted with parents in addition to a chart review to develop two case studies. Case studies are a methodology for describing processes, clinical procedures, and unique medical phenomenon in under-researched areas.[19] Practices described by parents as most beneficial to either outcomes or coordination of care were highlighted. Methodology including components of quality improvement and case studies was designed to develop a robust understanding of the process of anesthesia administration and accommodations made for children with ASD.

Results

Provider Champions

Recognizing unique needs for children with ASD during surgical procedures began with a group of providers passionate about treating this vulnerable population. Medical champions are leaders who contribute to changes in clinical culture that increase the likelihood of evidence-based practice implementation.[20] One of the first steps in the change process is identifying providers who were already incorporating accommodations into their practice and exceeding expectations to meet unique needs of children.[21] Creating an individualized plan of care is a well described intervention for children with ASD during surgical procedures.[14] However, implementing this plan of care in a busy surgical suite environment is challenging. Provider champions are needed to ensure practice changes that benefit children with ASD are sustainably integrated. A dedicated team of champions including nurses, advanced practice providers, anesthesiologists and surgeons joined together to create a protocol for managing children with ASD and their families. One of the beginning efforts of this team was the development of an ASD questionnaire to be filled out by parents of children scheduled for procedures (Table 1). These questions were discussed in a series of meetings with anesthesia providers based on their clinical expertise and finalized with input from parents and the hospital's family ambassador program. This program convenes caregivers to provide feedback on a variety of proposed changes at the hospital. This ensures policies are enacted with input from families who receive care in this setting. The primary purpose of the questionnaire was to identify children with ASD and secondarily to describe components of care that may be helpful to the family.

Identification and Preparation

As part of preparation for procedures, the hospital's ARC nurse meets with each family to discuss plan of care. These centers are integrated into many children's hospitals to explain procedures to families, overview pre- and postoperative instructions, and answer questions. ARC visits are predominantly conducted for same-day-surgeries and are ideal for identifying special needs or potential complications before procedures.

Starting in 2017, the providers at ARC consultations began asking every family if their child had ASD with the goal of correctly identifying 80% of children with this diagnosis. According to providers, this was the most significant practice change. After identification, an e-mail to the child's interdisciplinary team, which includes schedulers for the operating room and a member of child life, is generated. The ASD questionnaire was also integrated into the electronic medical record, making it more accessible to all providers caring for the child. The registered nurse for the case uses this information to develop a tailored plan of care based on caregiver responses. In this process, outpatient care providers are often consulted to provide information relevant to the child. If available, the case is assigned first for the day. Under normal circumstances, cases are scheduled according to age because patients are required not to eat or drink before the procedure. Typically, younger children are prioritized due to their risk of dehydration. However, children with ASD may become increasingly irritable if they are not able to eat until later in the day.[22] Parents identified this accommodation among the most helpful interventions. Furthermore, a designation that the child has a diagnosis of ASD appears on the operating room dashboard for procedures. This modification enables quick communication with the surgical team. Finally, during the COVID pandemic, children presenting for procedures required an negative COVID test. Because this is often difficult to obtain in the community, the team may plan to administer a rapid test when the child arrives at the hospital under mild sedation before the procedure takes place. This practice was especially appreciated by parents (Box 1).

Box 1
Identification and Preparation

- Meeting with the anesthesia resource center (ARC)
- Autism spectrum disorder (ASD) questionnaire (Table 1)
- Family coordination
- Develop a plan
- Team notification
- Electronic medical record (EMR) updates
- COVID-19 testing

Perioperative Area

Several accommodations for the perioperative area were implemented, which help facilitate anesthesia induction and streamline

Table 1
Computer Based Questionnaire

Does your child have a diagnosis of autism spectrum disorder?	Yes No
What age do you consider your child to be developmentally?	Free response
Please share how your child communicates best	Verbally, picture cards (eg, boards) sign language, gestures, iPad/communication device, other
What motivators would support your child while in the hospital environment?	Free response
Are there any behaviors that you would like us to be aware of in the hospital environment?	Free response
Would any of the categories below help your child when they feel upset or help to avoid distress?	Sensory electronics (listening to music, reading a book, watching TV/videos, playing video games, puzzles etc) Quiet environment (quiet time in room, dimmed lighting, door to room open/closed, avoid loud noises, etc) Tactile stimulation (playing with favorite toy, wrapping self in blanket or sheet, avoid being touched, etc)
Would you anticipate that your child would benefit from a multisensory device in the in the preoperative waiting room day of surgery (ROVER)?	Yes No
A premedication on the day of surgery aids in separation when your child enters the operation room. Would you like your child to receive	Oral version (liquid IV (the IV is a catheter placed with needle) Injection (needle) Intranasal (sprayed into the nose) None
Please let us know if in the past your child has	Had an adverse reaction to medication Benefited from a parental induction
Would being scheduled as the first case be helpful?	Yes No
Is there anything else we should now to help you and your child on the day of surgery?	Free response

postprocedural activities. As part of their accommodation plan, the ARC secured the funding for 2 ROVER (https://www.southpaw.com/relaxation-bubble-tube-rovers/) devices. These are multisensory, medical grade devices that can serve as distraction for the child by playing music, blowing bubbles, changing colors and projecting spin art on the wall. Additionally, iPads displaying preferred images or videos are often also used for distraction. It is standard at the hospital for children over the age of 9 months of age to receive a premedication to facilitate separation from the parent before anesthesia is given. Questions about premedication are asked in the ARC questionnaire and a plan is established with an ARC provider during this visit. Options typically include midazolam either orally or via nasal spray or ketamine either orally or via injection.[23] Some children are able to tolerate placement of an IV, in which case the midazolam or ketamine can be administered IV. Other patients are able to undergo a parental induction whereby the parent is present for an inhalation induction and the IV is placed thereafter.[24] These options are discussed with the parent during plan of care development. Tools for sensory engagement help distract the child while the anesthesia provider on the team initiates medication.

Several other changes to standard procedures take place in the perioperative area. For example, when nursing can identify a child with ASD, an effort is made to streamline post-procedural activities. The nurse often gives discharge education before anesthesia administration so that the parent can prioritize attending to their child after the procedure. Additionally, because children with ASD may become agitated with sequential changes in routine and novel sensory experiences, they are often not asked to change into a hospital gown. The procedure takes place in the child's own clothing. After separating from the child, parents have the option of receiving text message alerts about progress in the operating room. Although this is available for all children, parents of children with ASD found this especially helpful in anticipating their child's needs and reducing anxiety. While coordination of care for children with ASD was reported as most influential from the perspective of the provider, parents identified several additional accommodations in the perioperative area that were meaningful for their hospital experience. For example, parents noted that being able to bring a preferred item for their child facilitated separation from the family during anesthesia administration (Box 2).

Box 2
Preoperative Area

- Scheduled for first case
- ROVER use
- Medication plan
- Prioritize discharge education
- Clothing modification
- Parent messaging
- Preferred items

Operating Room

Once the child has successfully separated from the parent and anesthesia is initiated, the scheduled procedure takes place in the operating room (OR). To reduce the need for repeated anesthesia, care clustering is employed for children with ASD when procedures are clinically indicated. Care clustering is a time management strategy that reduces the burden of healthcare on the patient.[25] For children with ASD, some routine clinical tasks are not easily conducted without the use of anesthesia. Therefore, care clustering enables multiple tasks to be conducted under one administration of anesthesia. Although frequently requiring interdisciplinary coordination, providers can draw blood for labs, immunizations, and even dental care while the child is under anesthesia for another procedure. The most common subspecialties that collaborate on care in this context include dental, ear, nose and throat (ENT), orthopedics, general surgery, and urology. Parents reported greater satisfaction when they can plan for more than one procedure to take place under a single administration of anesthesia. Coordination between specialties, the family and the child's primary care team makes clustering possible. Other modifications for children in the OR include changes in medication administration. For example, it is often helpful to remove the IV before the child wakes up to avoid unnecessary sensory

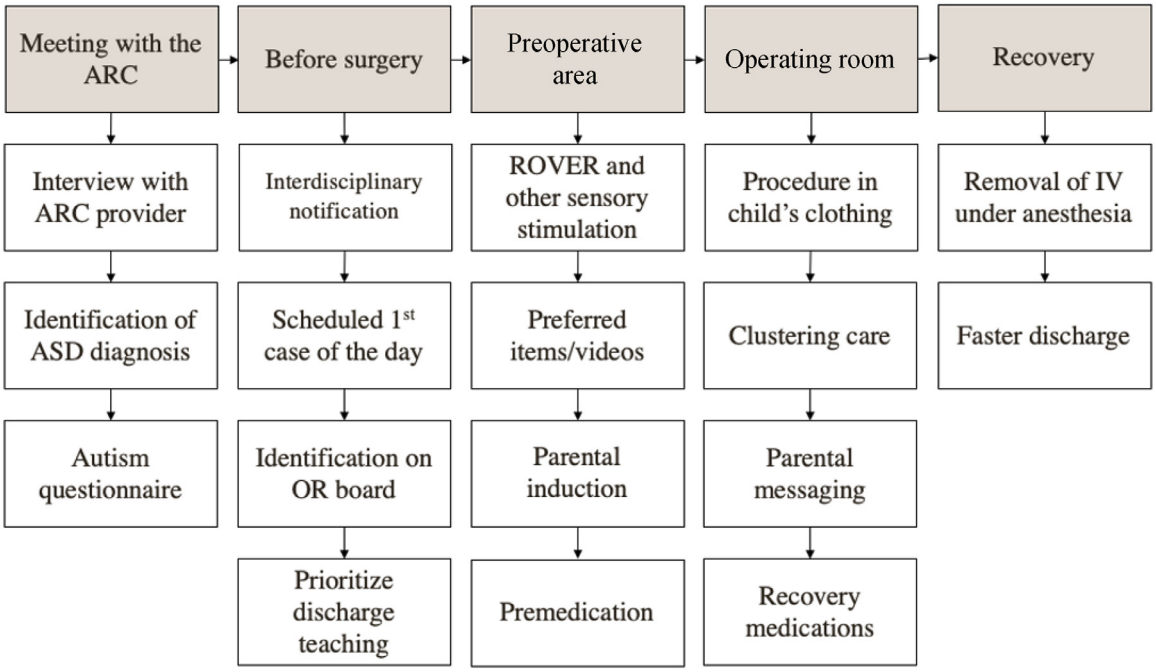

Figure 1. Accommodations process map. ARC, anesthesia resource center.

difficulties. Because children with ASD may have difficulty taking fluids orally immediately following the procedure, IV hydration is given before leaving the operating room. Additionally, acetominophen, antinausea medications and any other medications are given IV prior to leaving in OR (Box 3).

Box 3
Operating Room

- Clustering care
- Intravenous (IV) medications
- Intravenous (IV) removal

After Procedures

After the procedure has taken place, there are several accommodations that are made if a child has been identified with ASD. Firstly, when possible, an effort is made to maintain consistency between the nurse before and after the procedure. The parent is notified that the procedure is complete via a text messaging system so they may be ready in the recovery room when the child wakes up. Ensuring that familiar people are present after the procedure reduces changes in routine and child anxiety in the hospital setting. As previously mentioned, discharge teaching often occurs before the procedure takes place. This translates into a shorter period that the family spends with providers following the procedure. Caregivers often appreciate that the postsurgical time is curtailed to facilitate transportation out the hospital. Finally, the nurse may help transport the patient in the least stimulating route after they are discharged. Parents expressed appreciation for the ability to move more rapidly through postprocedure activities. When there was a medical indication for the child to spend more time in recovery before discharge, these modifications allows caregivers to devote more attention to their child. The described set of accommodations from standard practice for children with ASD requires a dedicated team of providers, collaboration with the family and a well-developed care plan. An accommodations process map is presented in Figure 1 (Box 4).

Box 4
Post Procedure

- Consistency in providers
- Abbreviated discharge teaching
- Transportation

Case Summaries

Two case summaries of patients that were seen by the ARC for surgical procedures are described. These children were identified with ASD during a preoperative visit and benefited from accommodations throughout their care.

Case 1

LS is a 17-year-old male with autism spectrum disorder and intellectual disability who is nonverbal and has self-injurious behaviors. He was admitted to the emergency department with significant stool burden demonstrated by x-ray. He presents with 3 weeks of worsening constipation, abdominal distention, nonobstructive bowel gas pattern and pain. His last bowel movement was 10 days ago. His home gastrointestinal treatment includes 17 g MiraLAX twice a day, 2 tabs 8.6 mg Senna twice a day, magnesium 400 mg tab twice a day with a fluid goal of 60 oz daily and 30 g of fiber daily. LS was scheduled for a day surgery for fecal disimpaction via cecostomy tube. He will follow up with gastroenterology and psychiatry for ongoing treatment.

Many of the accommodations previously described were implemented in this case. After discussion with the family, it was determined that the patient would need significant sedation for an enema and would not be able to tolerate nasal gastric tube placement for a MiraLAX cleanout, the standard care for constipation. This decision

took place with a surgeon and anesthesiologist champion familiar to the family. Interdisciplinary coordination and upfront communication with the family enabled this accommodation in practice.

LS was scheduled for first case of the day at the request of the parent. When the family arrived at the hospital, they were met in the parking garage by an OR nurse and transported directly to the perioperative area in a chair that could be reclined as needed. This change reduced sensory stimuli by avoiding the main entrance to the hospital. LS was able to tolerate the physical exam with the team's nurse practitioner upon arrival with distraction and redirection. This included an iPad with his favorite songs. LS was not required to change into a hospital gown or have a blood pressure cuff around his arm, the team took his heartrate. LS received 300 mg of ketamine via injection given by a familiar nurse. The team had previously determined that mask ventilation would not be attempted. He tolerated insertion of a peripheral IV on the first attempt, after which he received lactated ringers and was transported to the OR in his clothing. He was intubated and received 100 mg of succinylcholine, 4 mg of ondansetron and intervals of dexmedetomidine over 45 minutes totaling 84 mg. Following this medication administration, LS was sleepy but conscious and able to tolerate the preop process without escalation or aggressive behavior. The nurse used brief directions and was able to verbally calm him. Because this surgery took place during the COVID pandemic, this patient received sedation prior to receiving a rapid test for COVID, a requirement of the hospital. The nurse provided most of the discharge teaching at this stage to his mother.

LS was then able to be separated from his parent and transported to the OR in his clothing. Following a successful procedure, LS was brought out of the PACU anesthetized and his IV was removed. As he woke up, the stretcher was transferred into a chair and his mom helped him get dressed while his music was playing. His pain was well managed and vitals stable. Following a planned abbreviated discharge, LS was transported back to the car by the same route the family arrived. The visit took approximately 5 hours. Interdisciplinary communication that enabled these modifications was facilitated with the help of the child's outpatient psychiatry provider, another ASD champion, and the family.

Case 2

AG is an 8-year-old male with autism spectrum disorder, 1P36 deletion syndrome, aggression, chronic bilateral otitis media, hearing loss, obesity, and hypotonia. He is nonverbal and uses the iPad and sign language for communication. AG was admitted for day surgery for bilateral cerumen disimpaction. During this procedure, cerumen was debrided using a wax curette and he was also assessed for tympanostomy tubes, which were not needed. Earmold impressions were conducted under general anesthesia after the procedure to be used for hearing aids. He also received an echocardiogram, electrocardiogram, ear, nose and throat scope, and blood drawn for lab work at the request of his outpatient clinical team. AG's mother coordinated with an ARC provider to schedule several procedures at the same time. While this accommodation required additional organization from the parent and provider champions, it ultimately reduced distress to the child over multiple visits. AG is followed by neurology, cardiology, and developmental pediatrics.

This child was known to the care team and a familiar set of providers was assigned to the case. This helped the family feel more comfortable and ensured less disruption in routine for the child. The family was traveling far from the hospital and was scheduled for first case of the day to limit wait times. During the perioperative physical exam, blood pressure was taken manually to avoid additional sensory stimulation of noises and an automatic cuff. AG was able to tolerate this visit with redirection. The ROVER device was also used for this patient as distraction and his parent brought a favorite toy from home. Prior to the operation, the parent was permitted to stay with AG for a longer period to reduce anxiety and receive upfront discharge teaching. AG received 15 mg of midazolam syrup, which the nurse determined was not sufficient sedation. He then received 200 mg of ketamine via injection, after which he was able to tolerate a peripheral IV insertion followed by a rapid COVID test. Thereafter, he received 50 mg then an additional 30 mg propofol, 4 mg of ondasetron, 10 mg of dexamethasone, and 15 mg of Ketorolac given IV. Lactated ringers were also administered and 320 mg Ofirmev was given over 60 minutes.

AG was calm, able to be separated from his parent without escalation of behaviors or aggression and transported to the OR in his clothing. Following the procedure, the IV was removed when AG was waking up. Pain was well managed and his vitals stable. His mother helped prepare for transportation out of the hospital with planned abbreviated discharge instructions. The visit took approximately 7 hours total. In this case, the ARC helped coordinate between multiple outpatient providers to ensure tests that would have been otherwise been difficult to obtain were conducted under anesthesia.

Both exemplary cases required a dedicated care team both in preparation and in the perioperation area, involving frequent and early communication with the family. Both parents were appreciative to work with familiar providers and coordinate a detailed plan of care preemptively for a smoother visit. A tailored set of accommodations helps ensure patient and staff safety, increases satisfaction with care provided and improves patient outcomes.

Conclusion

Children with ASD represent a significant proportion of patients receiving anesthesia-involved procedures and they need an individualized plan of care. These children are more likely than neurotypical peers to develop medical conditions that require surgical intervention and often require anesthetics to tolerate minor procedures. As illustrated by a series of case studies, working closely with families to develop a plan of care is critical to optimizing patient outcomes and satisfaction. This begins with identifying patients with ASD prior to surgery and implementing a tailored set of accommodations relevant to the child and family. Accommodations by provider champions during surgical procedures provides a model of care for all providers to facilitate positive healthcare encounters for children with ASD and others with sensory challenges. This review serves as a template for accommodating surgical practices that include anesthesia, so they are sensitive to specific needs of children and families.

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